

Sexuality with myotonic dystrophy

Presentation by :

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Learning objectives

1

Attendees will be able to define important terminology related to sexual function, sexual activity, and intimate relationships.

2

Attendees will learn about two projects related to sexuality in the neuromuscular/DM community.

3

Attendees will learn some strategies for pursuing healthy, fulfilling sexual activities.

What is sexuality?

Includes

Biological sex

Gender identities and roles

Sexual orientation

Eroticism

Pleasure

Intimacy

Love life

Reproduction

Manifests as

- Thoughts
- Fantasies
- Desires
- Beliefs
- Attitudes
- Values
- Behaviors
- Practices
- Roles
- Relationships



What is sexuality?

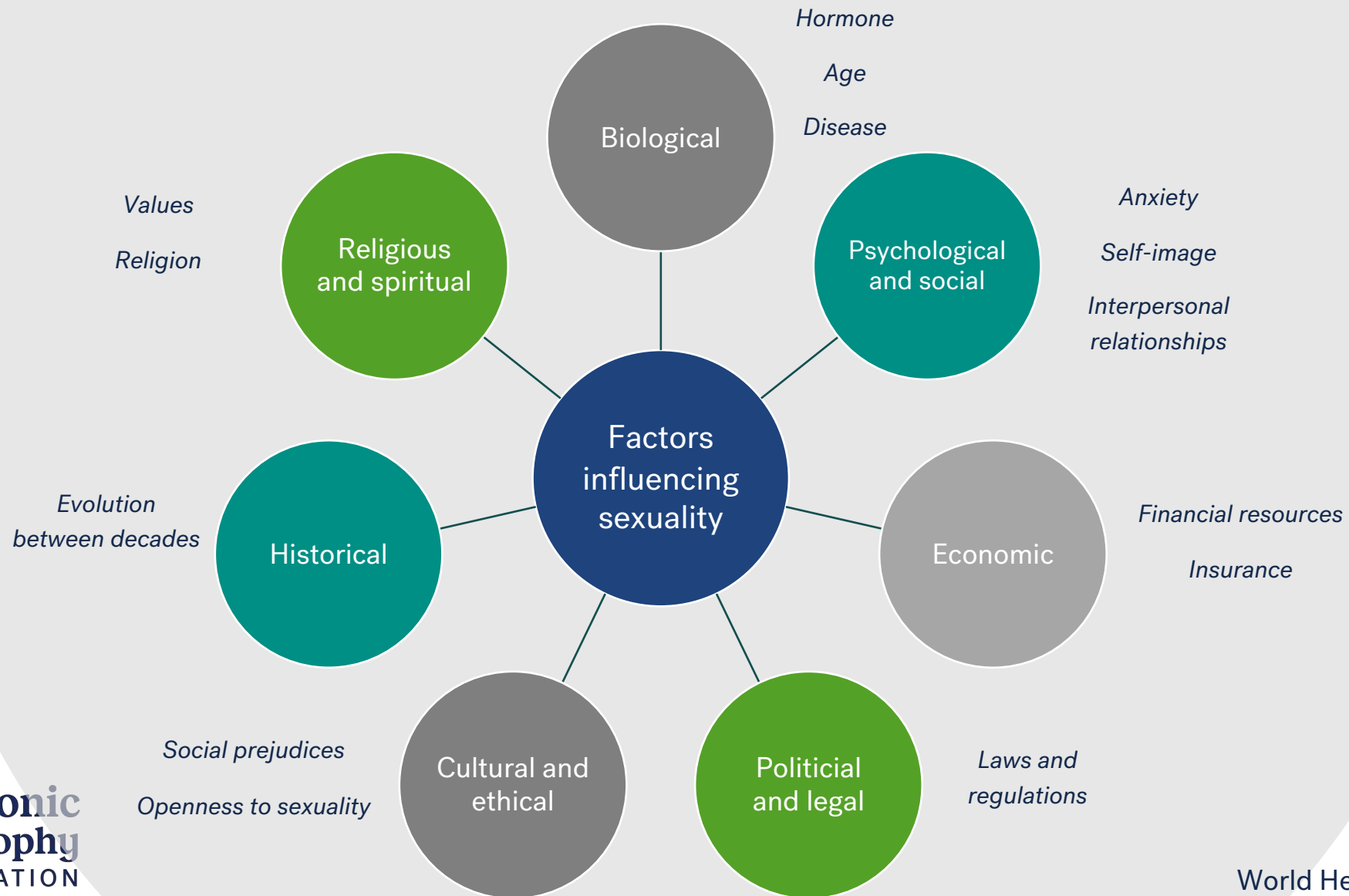
Fundamental needs

Unique

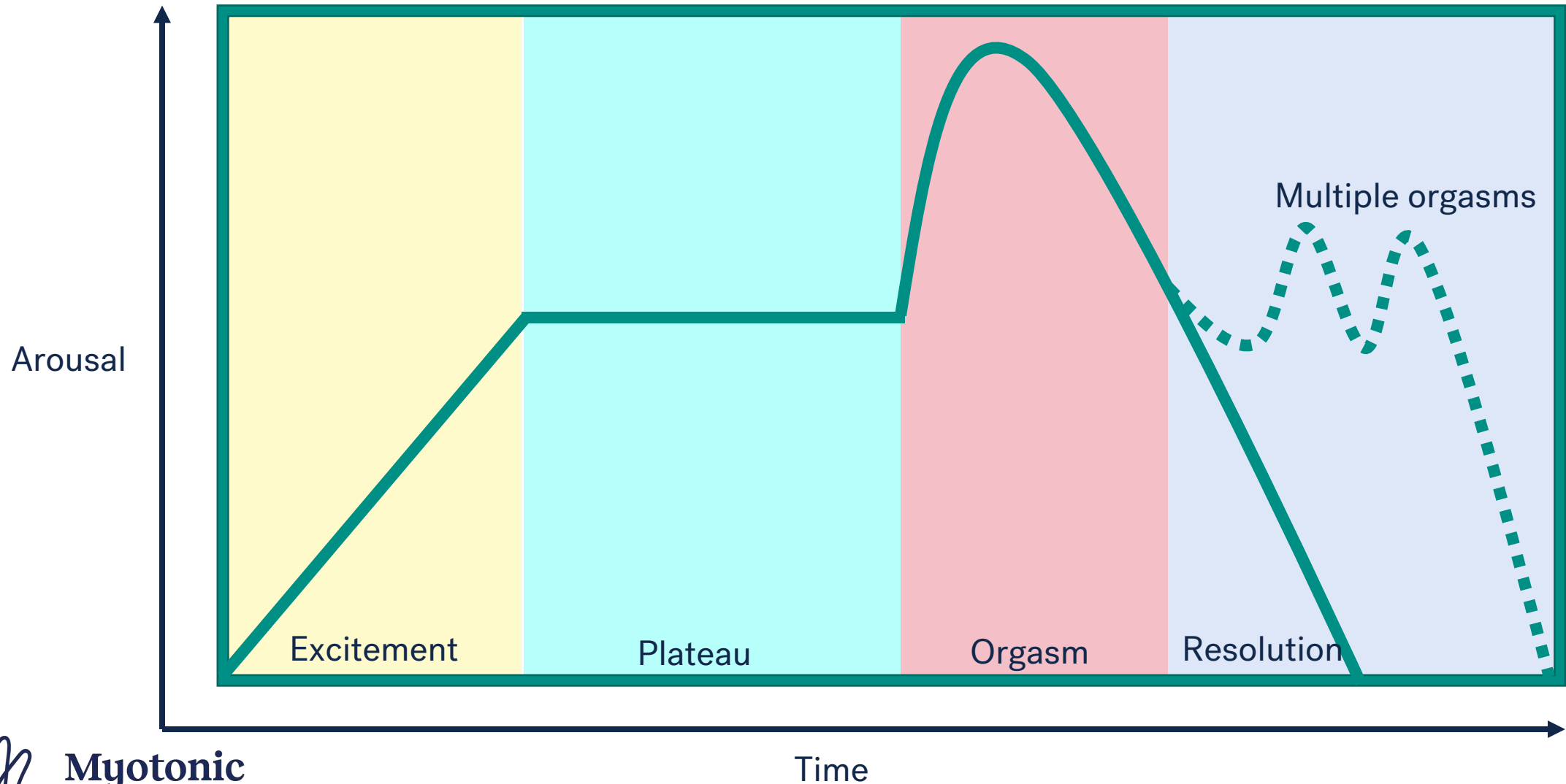
Experienced differently and
importance in a person's life varies

Evolves and changes over the
course of an individual's life.

Factors influencing sexuality

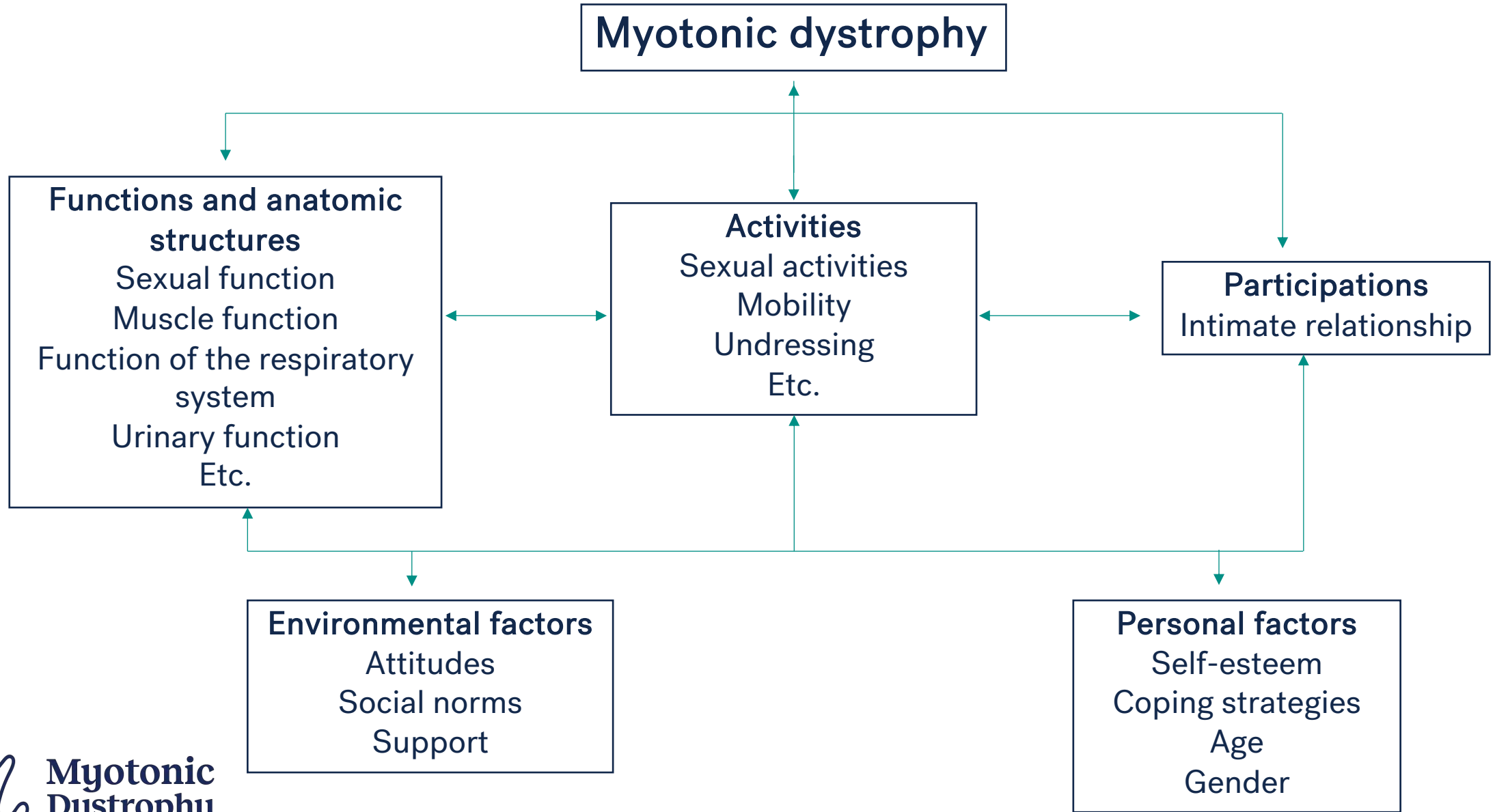


Sexual response adapted from the model of Masters & Johnson



Sexual function and intimate relationships

- **Sexual function** (mental and physical functions) :
 - Excitement / arousal phase : desire, libido, sexual interest
 - Plateau / preparatory phase: penile or clitoral erection, lubrication
 - Orgasmic phase: muscle contractions, ejaculation
 - Resolution phase: satisfaction, relaxation, absence of pain
- **Intimate relationships** :
 - Romantic relationships
 - Spousal relationships
 - Sexual relationships
- **Sexual activity**: caressing, masturbation, foreplay and intercourse



How can sexual function, sexual activities and intimate relationships be affected by myotonic dystrophy?

Sexual function :

- Erectile dysfunction
- Decreased vaginal lubrication
- Pelvic floor muscle dysfunction
- Low sexual desire
- Pain during sexual activities

Other function :

- Muscle weakness
- Fatigue
- Loss of mobility
- Urinary and anorectal dysfunction
- Cardiorespiratory impairments
- Etc.

Almost no research
evidence !!!!

Project 1 : Prevalence of urinary incontinence and other pelvic floor disorders in women with myotonic dystrophy type 1

Isabelle Fiset-Paulhus, PT; Mélanie Morin, PT, Ph.D.; Cynthia Gagnon, OT, Ph.D.

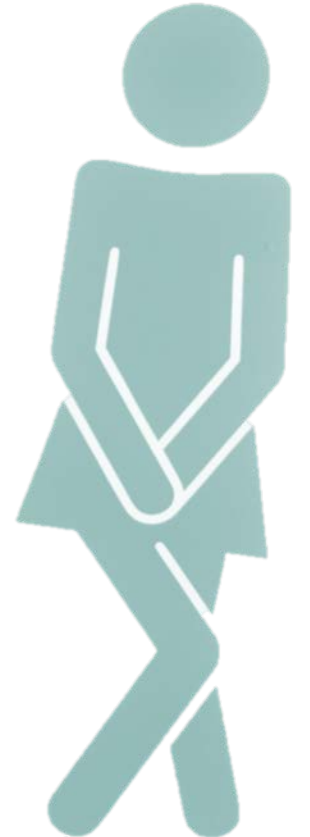
Data collection & analysis completed

Article in production



OBJECTIVES :

- Assess the prevalence, characteristics and impacts of urinary incontinence and other pelvic floor disorders in adult women with myotonic dystrophy type 1
- Assess the **sexual function**
- Explore the impact of age, phenotype, genotype, muscle weakness and number of deliveries on these symptoms



Project 1 : Prevalence of urinary incontinence and other pelvic floor disorders in women with myotonic dystrophy type 1

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METHODS :

- Epidemiological study performed in Quebec, Canada
- Recruitment: patient registry of a neuromuscular disease's clinic at the Jonquière Hospital (CIUSSS Saguenay-Lac-St-Jean)
- Interview using 4 validated questionnaires + general questionnaire

Inclusion criteria
Women
≥ 18 years old
Confirmed diagnosis of myotonic dystrophy type 1 (DM1)

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RESULTS :

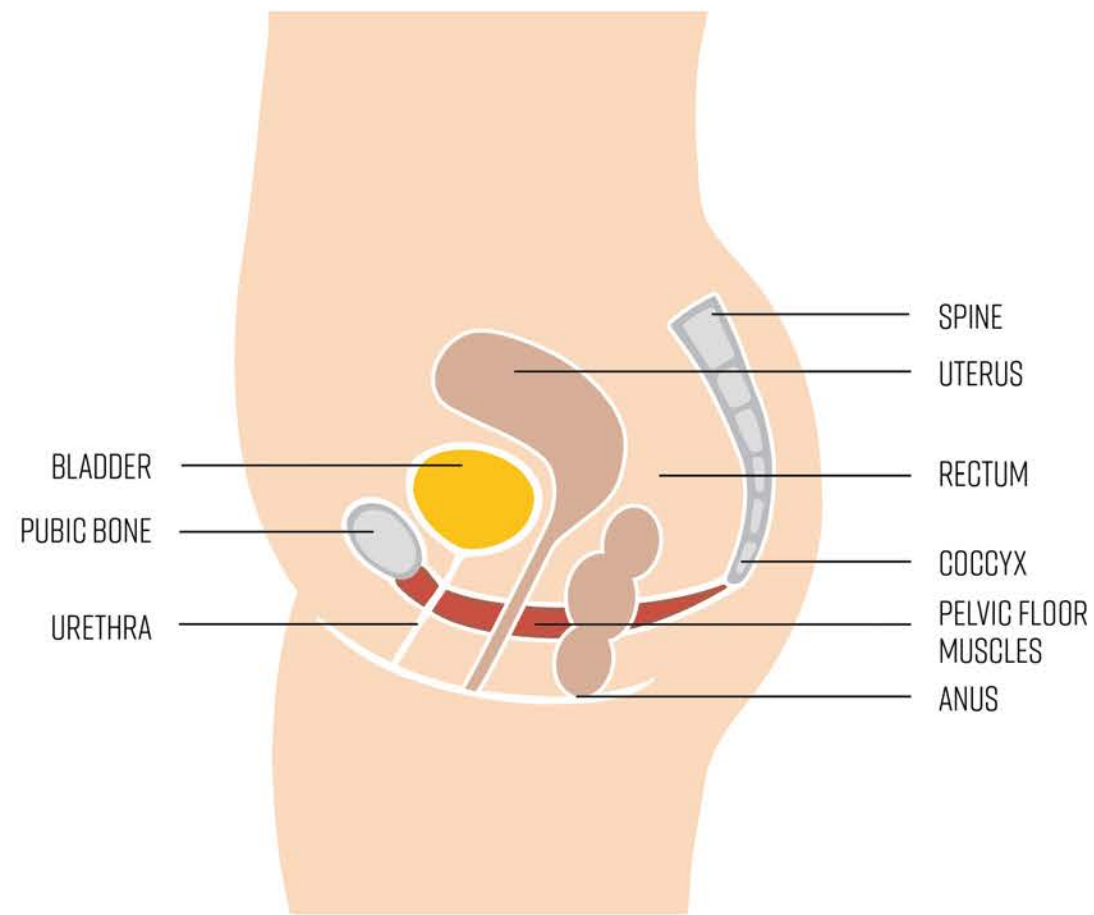
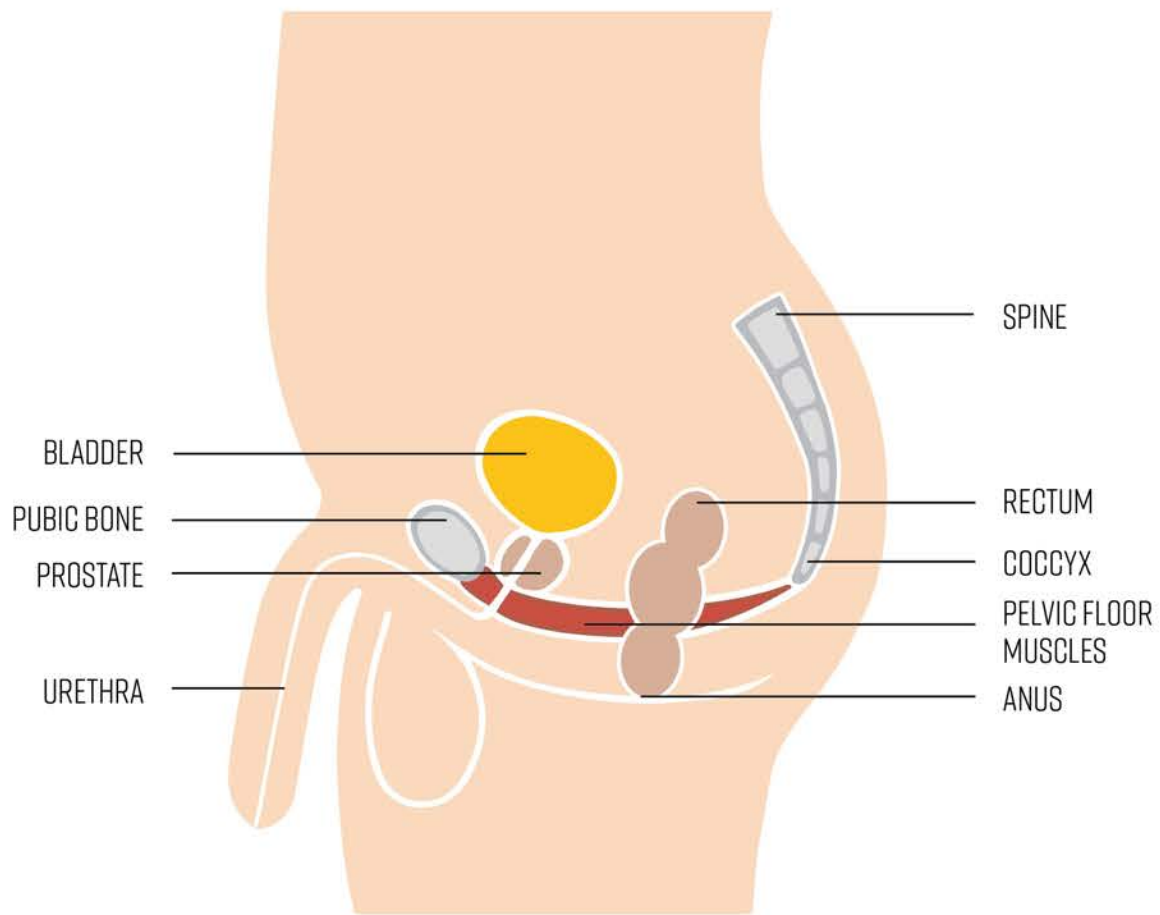
80 participants

Age : 23 to 78 years old

75% were sexually active

- Urinary incontinence: 60.6%
- Abdominal pain: 66.3%
- Anal incontinence: 56.3% (include stool and flatus)
- Fecal incontinence: 26.3%
- Pelvic pain: 22.5%
- Constipation: 40.0%
- Sexual dysfunction: 18.3%
 - Hypoactive sexual desire
 - Low lubrication
 - Pain or discomfort during vaginal penetration: 43.3%
 - 20% had this symptom at least half the time

Pelvic floor muscles



Project 2 : Clinical practice guidelines on roles and interventions in physical therapy to promote sexuality in adults with neuromuscular disorders

Isabelle Fisette-Paulhus, PT; Cynthia Gagnon, OT, Ph.D.; Julie Fortin, M.Sc.; Annie Plourde, Ph.D.; Marjolaine Tremblay, SW, M.Sc.; Laura Girard-Côté, PT; Mélanie Morin, PT, Ph.D.

Clinical practice guidelines soon to be published

Article submitted to Physiotherapy Canada Journal



INTRODUCTION :

- Neuromuscular disorders :
 - Diseases that affect function of the muscles with alteration to the muscle itself or peripheral nerves
 - > 200 different diagnoses
 - Wide range of signs and symptoms
 - Includes myotonic dystrophy



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Summary of the results from the Heatwole et al. (2012, 2015) studies


Impairments/limitations	DM1 (n=119 to 125)	DM2 (n=34 to 37)
Pain during sex	15.3%	33.3%
Impaired sexual function	57.6%	67.6%
Limited sexual positioning	Not reported	70.6%
Decrease sexual contact	53.8%	58.8%

Results from the Christopher project Report to the Myotonic Dystrophy community: Sexual/intimacy problems (DM1 = 32%) vs (DM2 = 44%)



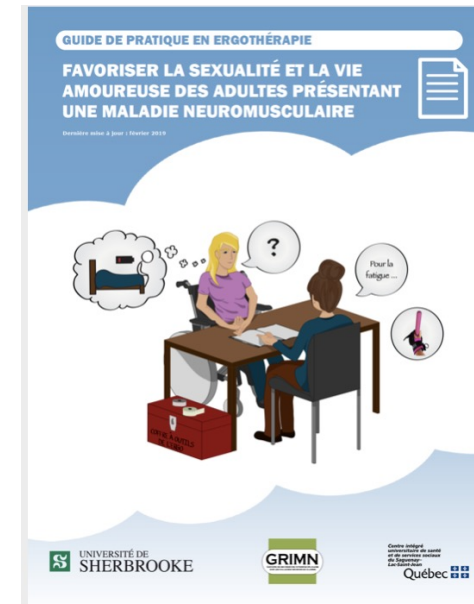
Project 2 : Clinical practice guidelines on roles and interventions in physical therapy to promote sexuality in adults with neuromuscular disorders

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 60% of healthcare professionals believe that sexual difficulties should be discussed, but only 6% frequently engage the discussion

OBJECTIVES :

1. To document impairments in adults with neuromuscular disorders that can interfere with sexual activities and to propose physical therapy interventions.
2. To recommend approaches to discuss sexuality.
3. To highlight issues that require expertise in pelvic floor rehabilitation.



Interventions

Physical activity

- ✓ Improves mental and physical well-being
- ✓ Direct impact on sexual function
- ✓ Indirect impact on sexual activities (maintenance or improvement of function, cardiorespiratory endurance or muscle strengthening)



Physical inactivity can increase the risk of developing sexual dysfunction.

Muscle weakness

- Preliminary studies show beneficial impact of exercise on muscle weakness
- Recommended having a muscle strengthening program for maintenance of capacities
- Tips to compensate for muscle weakness :
 - ✓ Modification sexual position, be creative
 - ✓ Sexual activity \neq penetration
 - ✓ Practice position before trying it in a sexual context
 - ✓ Use furniture or sexual objects
 - ✓ Weakness in the hand is frequent in DM1 : some sexual objects like vibrators are hand-free



Fatigue

- ✓ Determine when energy level is at highest and plans sexual activity around it
 - ✓ Mornings are usually when the energy is at the highest
- ✓ Plan rest period before and after sexual activities
- ✓ Penetration = more energy



Contractures and reduced range of motion

- ✓ Stretching before sexual activities are good way to help position and stay away from injury.
- ✓ Heat can be applied to relax the muscles*
- ✓ Some adapted positions may be more favoured depending on contractures. Physical therapists can help you in finding stretching exercises and adapted positions.

*Hot showers can help reduce tension in the muscles before sexual activity, but you have to be careful if you have low blood pressure.



Physical therapy

- Developing adapted exercise program

Erectile dysfunction

70-72% in DM1

- ✓ Negative impact of lifestyle habits on erectile function (obesity, physical inactivity, diet, tobacco, alcohol, drugs)
- ✓ Importance of pelvic floor muscle :
 - ✓ Contraction of pelvic floor muscle → decreases venous return from the cavernous tissues and help erection
 - ✓ Can help penetration and maintain of erection during penetration
 - ✓ Partners can do contraction around the penis during anal or vaginal penetration to increase pressure and help erection



Physical therapy

- Education
- Personalized program for pelvic floor muscles
- Neurostimulation, biofeedback

Female lubrication

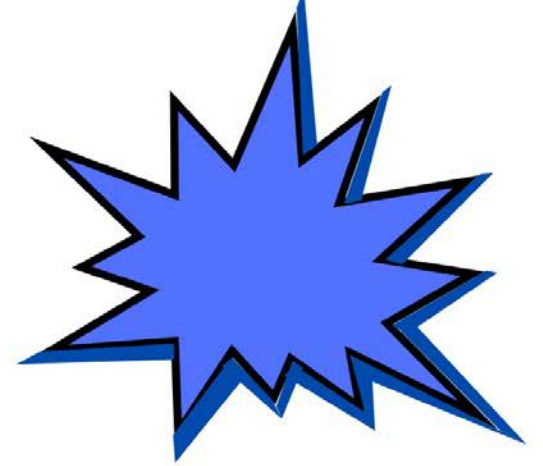
Lubricants	+	-
Water based	<ul style="list-style-type: none">- Most accessible- Can be used with condoms or other sexual objects	<ul style="list-style-type: none">- Dry quickly, need to reapply
Silicone	<ul style="list-style-type: none">- Can be used in water and with condoms- Longer lubrication	<ul style="list-style-type: none">- More expensive- Can't be used with silicone products- Difficult to wash off
Oil based	<ul style="list-style-type: none">- Low cost- High hydration and moisturizing	<ul style="list-style-type: none">- Can't be used with condoms- Can stain clothes

Physical therapy

- ✓ Pelvic floor muscle exercises
- ✓ Vibratory stimulation
- ✓ Transcutaneous electrical stimulation



Pain



- 86-88% in DM1 and DM2
- Importance to identify the cause of pain (tensions, myotonia, neurogenic pain, dryness, etc.)
- ✓ Schedule sexual activities at time when the pain is less intense and synchronizes with medication, level of fatigue and stress
- ✓ Relaxation and rest after and before sex can help reduce pain
- ✓ Modification in position (overload, back pain, vaginal penetration)



Physical therapy

- Pelvic pain: exercises, stretching, neuromuscular stimulation, manual therapy, biofeedback, dilatator

Incontinence

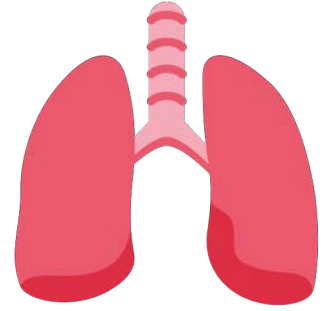
- ✓ Lifestyle habits that can have an impact on urinary symptoms :
 - ✓ Weight loss
 - ✓ Increase physical activity
 - ✓ Smoking cessation
 - ✓ Decrease caffeine consumption
- ✓ Water intake
- ✓ Pelvic floor muscle exercises
- ✓ Emptying the bladder before sexual activity and putting a protection on the bed can decrease anxiety associated with leaks.



Physical therapy

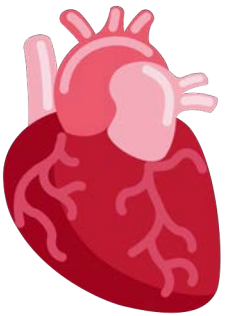
- Education, bladder diary
- Exercises
- Neuromuscular stimulation
- Proprioceptive exercises
- Biofeedback

Respiratory and cardiac implications



To reduce breathing difficulty and decrease intensity of the activities:

- ✓ Avoid sexual activity one hour after eating
- ✓ Don't consume alcohol three hours before sexual activity
- ✓ Avoid hot, humid or cold environments
- ✓ Plan sexual activity when well rested
- ✓ Some strategies can decrease dyspnea (posture, pursed lip breathing, diaphragmatic breathing)



Positioning

- Sexual activity ≠ penetration
- Respect capacities of **BOTH PARTNERS**
- Take into consideration:
 - Maintain of position
 - Movement into the position
 - Transferring between position
- Adaptations, equipment : pillow, bed helper, bean bag, electric bed
- Practice positions before sexual context



Physical therapy

- Recommendations
- Education on equipment

First position : on the back

Activities possible:

- Caresses
- Masturbation
- Oral sex
- Vaginal or anal penetration

Benefits:

- Women or men
- Less effort
- Better support



Second position : on the side, face to face

Activities possible:

- Caresses
- Masturbation
- Oral sex in reverse position (69)
- Vaginal penetration

Benefits:

- Allows both partners to participate
- Less effort
- Interesting positions if both have limitations

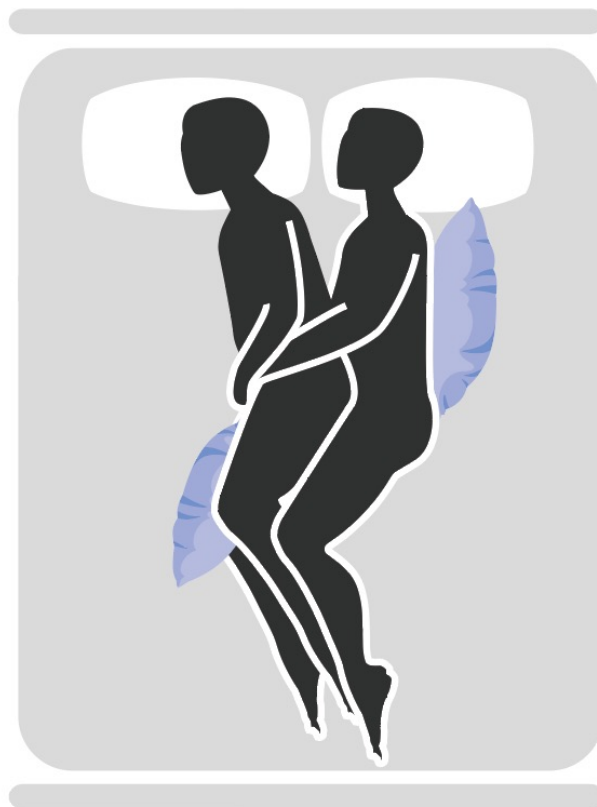
Third position : on the side, spoon or perpendicular

Activities possible:

- Caresses
- Masturbation
- Vaginal or anal penetration

Benefits:

- For women or men
- Less effort



Fourth position : sitting

Activities possible:

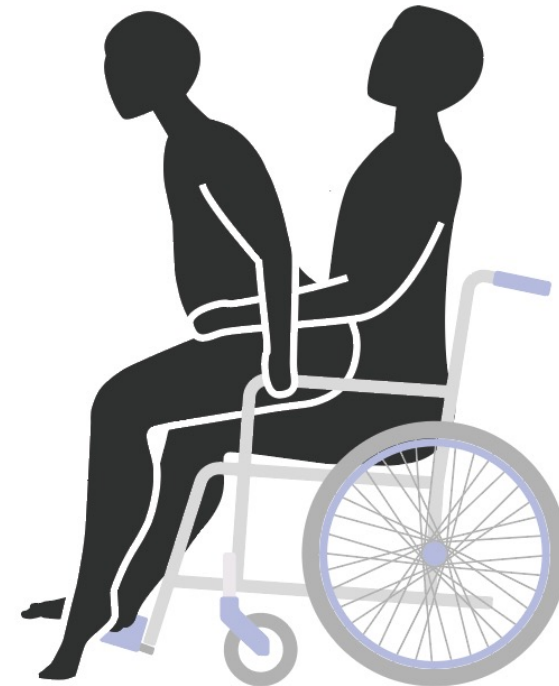
- Caresses
- Masturbation
- Oral sex
- Vaginal penetration

Men sitting: partner face to face, back or side

Women sitting: possibility of moving the buttocks forward on the chair for penetration or oral sex, but this decreases the support

Benefits:

- Passive position for the person seated
- Decreases the number of transfers



Fifth position : on the abdomen

Activities possible:

- Masturbation
- Vaginal and anal penetration

Benefits:

- Women or men (anal penetration)
- Facilitates sex with penetration

Middle of the bed or edge of the bed (*doggy style*)



AVOID IF:

- Inability to roll over onto your back
- Severe weakness of the upper limbs
- Breathing difficulty

Sex objects

Masturbation : women



Massage glove



Magic wand



Vibrating panty



Handy harness



Dildo



Magic mount



Finger vibrator



We vibe



Hands-free vibrator

The pictures are examples of different sexual objects. No reference is mentioned as we don't want to encourage one specific brand or sex shop.

Sex objects

Masturbation : men

Penis stimulator



Vibrator penis ring



Male masturbator



Kneeling mount



We vibe

The pictures are examples of different sexual objects. No reference is mentioned as we don't want to encourage one specific brand or sex shop.

Sex objects

Penetration



Thigh strap on

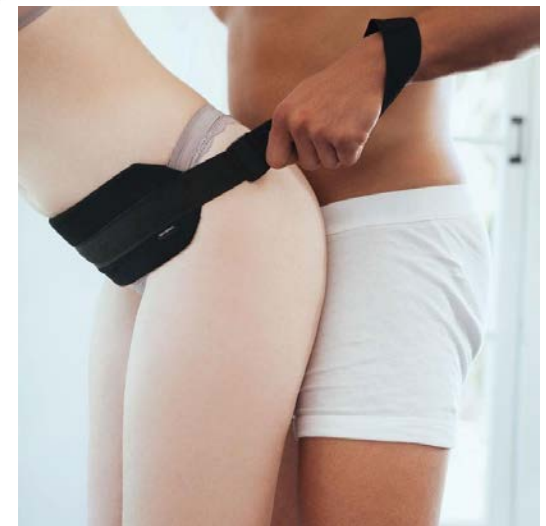
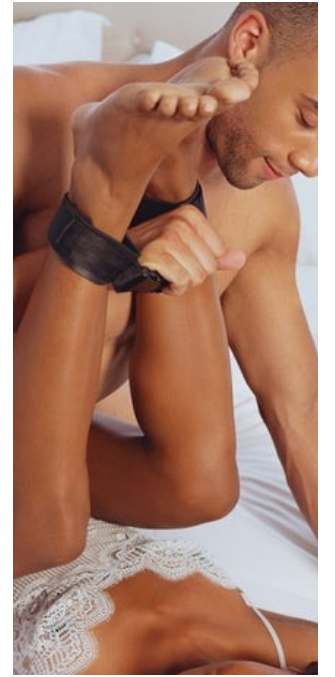
Ohnut



Penis sleeve



Sling and strap



The pictures are examples of different sexual objects. No reference is mentioned as we don't want to encourage one specific brand or sex shop.

Conclusion

- Sexuality and intimacy are part of a fundamental need.
- Neuromuscular diseases can affect sexuality.
- There are many ways to adapt your sexual life.

- Future studies should focus on developing interventions for improving sexual function.



Thank you!



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Questions ?

