




# **DM & INTIMACY TALKING TO YOUR DOCTOR**



Centre intégré  
universitaire de santé  
et de services sociaux  
du Saguenay-  
Lac-Saint-Jean

Québec 

**Le Parcours**   
Centre de réadaptation en déficience physique

**Cynthia Gagnon, PhD, OT, Associate Professor, Université de Sherbrooke**

**Annie Plourde, biol. Ph.D., Knowledge broker Clinique des maladies neuromusculaires  
de Jonquière, CIUSSS Saguenay-Lac-St-Jean**

**Groupe de recherche interdisciplinaire sur les maladies neuromusculaires**

**ADULT SUBJECT MATTER**

**VIEWER DISCRETION IS ADVISED**

**THIS SHOULD ~~NOT~~ BE TRY  
AT HOME**

# INTIMACY/SEXUALITY AND DM 1

- What I should know
- What my partner(s) should know
- What my healthcare team should know
- How to address this with my healthcare team
- How to address it within the family

**General advice that may not reflect your religious/personal beliefs, values and expectations**

**WHAT YOU  
AND YOUR PARTNER  
AND YOUR HEALTHCARE TEAM  
SHOULD KNOW**

# SEXUALITY OR WHAT ARE WE REALLY TALKING ABOUT

- "Sexuality is a **central aspect** throughout life **identities and eroticism, pleasure, reproduction**. expressed in **thoughts, beliefs, attitudes, practices, roles** sexuality can include **all of them are** [...] **experiences, attitudes, desires, behaviours, relationships**. While **some dimensions, not all are** experienced or expressed.



(WHO, 2006)

# SEXUALITY ... NOT A SIMPLE PHYSICAL ACT

- **Physical act**
- Affection
- Love's life
- **Self-esteem**
- **Reproduction**
- **Couple's life**
- **Social relationships**
- **Sexual Identity**
- **Ethics**
- **Etc.**

# PHYSICAL ACT : TO DO OR NOT TO DO BUT WHAT ?

- Making love
- Caress
- Masturbation
- Kissing
- Hugging
- Touching



**HOW DM1 CAN INFLUENCE  
THE EXPRESSION OF MY  
SEXUALITY ?**



# **HOW DM1 CAN INFLUENCE SEXUALITY : PHYSICAL PART**

- **Muscular system**
  - **Decrease muscle strength**
    - **Difficulty/Unable to assume certain positions**
    - **Decrease endurance**
    - **Decrease ability to close hand/myotonia :  
masturbation/caress**
  - **Presence of pain**
    - **Difficulty/Unable to assume certain positions**
    - **Fear of having pain during the process**

# POTENTIAL SOLUTIONS

Occupational therapist

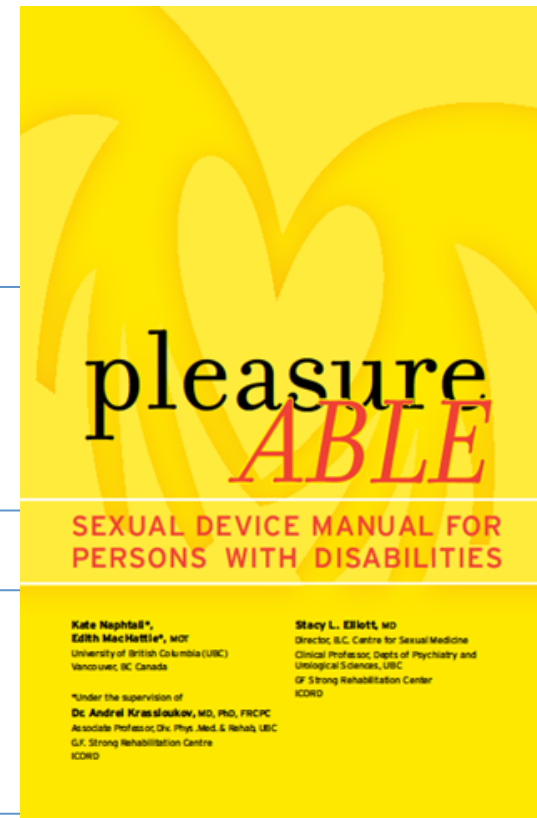
- Adopting new positions
- Adaptation (sexual devices/hand free)
- Energy conservation technique

Physical therapist

- Adopting new positions
- Exercise

Sexual counsellor/  
psychologist

- Adaptation (sexual device)
- Discussing new role (women more active than her partner)
- Counselling



# HOW DM 1 CAN INFLUENCE SEXUALITY : PHYSICAL PART

- **Central Nervous system**
  - **Fatigue**
    - Decrease interest
    - Decrease endurance
  - **Hypersomnolence**
    - Decrease interest
    - Decrease opportunity
  - **Apathy**
    - Trouble initiating
  - **General cognitive functioning**
    - Risk-taking behaviors

# POTENTIAL SOLUTIONS

Doctor

- Medication
- Fatigue/hypersomnolence ; Modafinil-Ritalin

Sexual  
counsellor

- Counselling about new role/new technique to initiate

Occupational  
therapist

- Energy conservation technique
- Adaptation/ to less demanding positions

# HOW DM1 CAN INFLUENCE SEXUALITY :

## PHYSICAL PART

### Genito-urinary system

- Erectile dysfunction
  - Between 24.1% and 36.7% of men
  - Medication may be given
- **Gynecological problem**
  - Painful menstruation
- **Urinary incontinence**
  - Medical consultation
  - Hygiene technique
- **Intestinal problem**
  - Medical consultation
  - Sexual counsellor
  - Hygiene technique

# HOW DM1 CAN INFLUENCE SEXUALITY : PHYSICAL PART

## Cardiac system

- Patient and partner may be fearful of having sexual relationships

## Respiratory system

- Nocturnal ventilation

# WHO DOES WHAT



# SEXUAL MEDICINE PHYSICIANS OR PHYSIATRISTS (MD)

- Maximizing sexual physiology and reducing the medical issues
  - Medications
  - Pain
  - Bladder and bowel continence
- Other physicians (urologist, gynecologist, neurologist, etc) may also have valuable expertise



# OCCUPATIONAL THERAPIST

- Teaching skills such as how to:
  - organize a **daily routine** to allow time and energy for sexual activities
  - manage **personal hygiene** before and during sexual activities
  - **compensate** for reduction or loss of typical body functioning in order to sexually satisfy self and/or partner
  - alter or eliminate **environmental barriers** to improve the quality of sexual activity (e.g. poor lighting, inadequate bed system etc.)
- Adapt sexual devices to meet the abilities of clients
  - adding switches
  - making 'hands free' options

# PHYSIOTHERAPIST

- Educate and assist clients with skills such as:
  - transferring from wheelchair to bed
  - repositioning in bed
  - maintaining balance
  - maximizing comfort in sexual positioning alone or with partners
  - compensate for reduction or loss of typical body functioning in order to sexually satisfy self and/or partner
  - perineal reeducation (advanced practice)

# NURSES

- Can assist with the execution of many of the suggestions given by the OT, PT or MD, and are critical in assisting with the overall medical management.
- Sexual Health Clinicians (SHC) are nurses specialized in the area of sexual health. They are experts in educating clients and their partners on the complex changes to sexual function as a result of chronic illness or disability, and are qualified to make specific suggestions to enhance sexual functioning and/or fertility.

# **SOCIAL WORKER/PSYCHOLOGIST**

- **Social Workers**
  - Can play a large role in educating and counseling partners and families around sexual and fertility issues.
  - Can also assist with funding options for the purchase of equipment.
- **Psychologists**
  - Explore in depth with clients the many different emotional components of sexuality such as self esteem, assertiveness, and positive self-talk, as well as collaborate with partners and family around sexual and fertility issues.
  - Psychologists can also address trauma around sexuality.

# REHABILITATION SEXUAL COUNSELLORS

- Not found everywhere
- University training
- Holistic approach around sexuality

# **HOW TO TALK TO MY HEALTHCARE TEAM**

**But why do I have to  
do it ?**

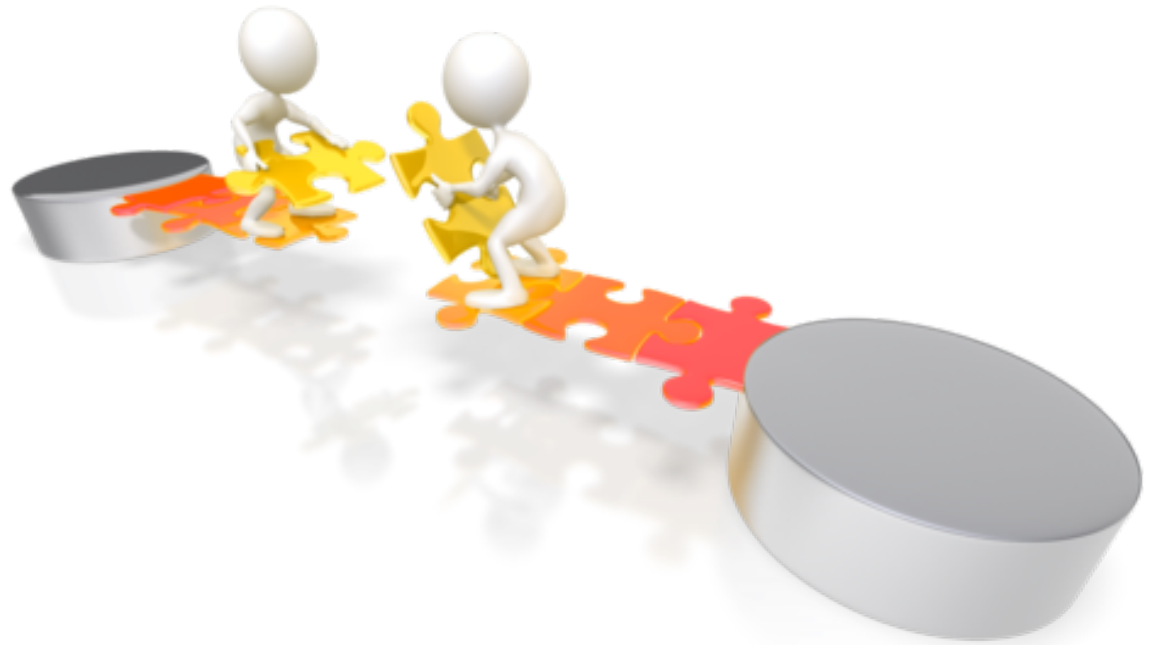
# TABOU... Sexuality is not often bring up with patients ...

« It does not exist! »



« Of course, but not my role? »





**BRIDGING THE GAP**

**A DUAL RESPONSIBILITY**



# HOW TO APPROACH YOUR HEALTHCARE TEAM

I feel comfortable talking about

1. Make a list of your concerns
2. Choose a person in your healthcare team that you feel at ease to talk to
3. Make an appointment if possible or address it during your annual visit
4. Make a follow-up visit if needed



Avoid the  
doorknob  
approach

# **HOW TO APPROACH YOUR HEALTHCARE TEAM**

## **I feel less comfortable talking about sexuality**

- 1. Make a list of your concerns**
- 2. Choose a person in your healthcare team that you feel most comfortable with**
  - 1. Choose someone close to you that can address this with your healthcare providers (spouse, carer, etc)**
  - 2. Make a text/list about your problem to share with your healthcare providers to answer**
- 3. Make an appointment if possible or address it during your annual visit**
- 4. Make a follow-up visit if needed**

How your healthcare  
professional should talk  
to you about sexuality

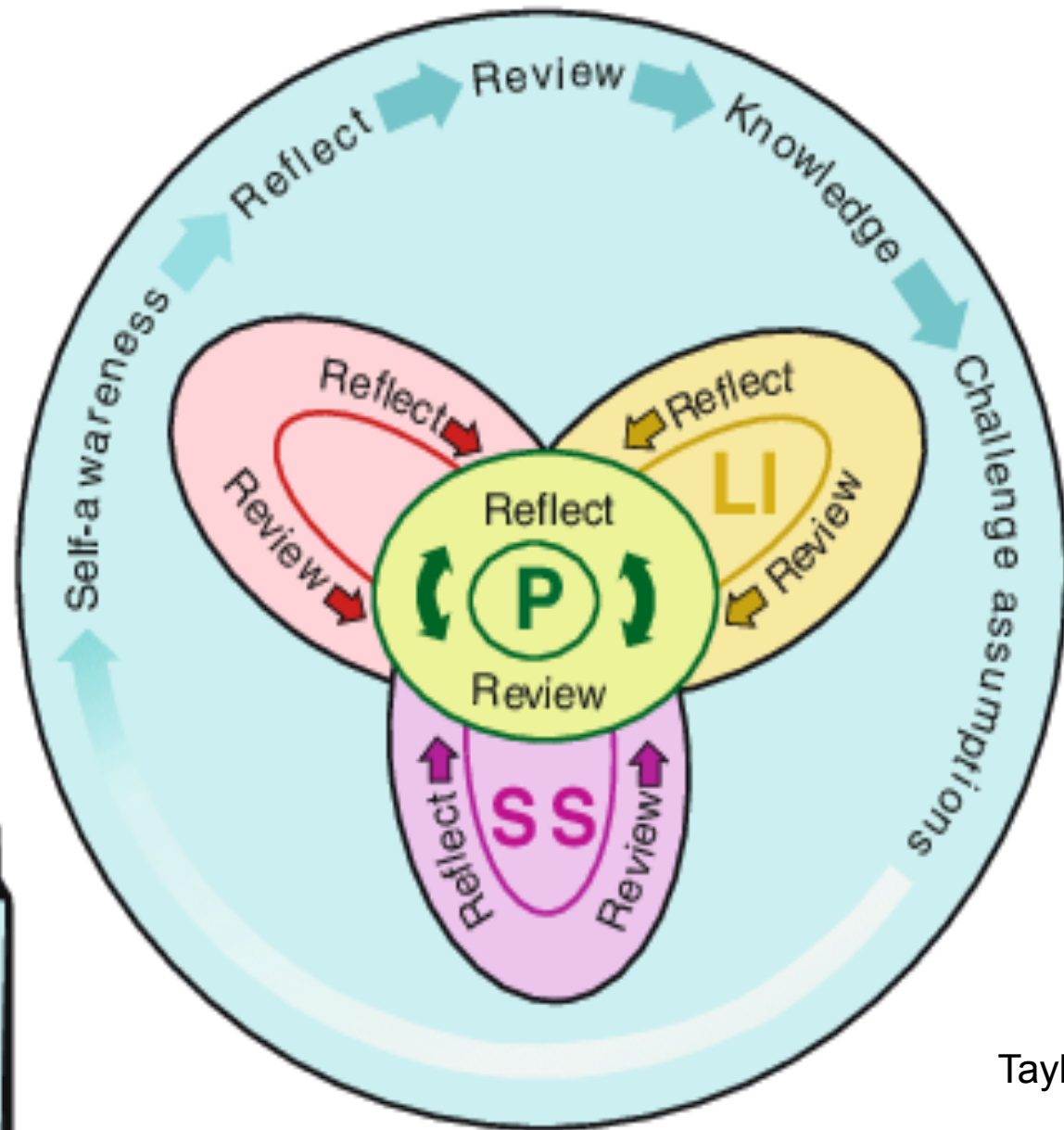
# **EX-PLISSIT**

(Annon 1976, Taylor 2006)



# The Extended PLISSIT Model

KEY	
<b>P</b>	Permissiongiving
<b>LI</b>	LimitedInformation
<b>SS</b>	SpecificSuggestions
<b>IT</b>	IntensiveTherapy



# EX-PLISSIT

**LEVEL 1**  
**PERMISSION (GIVEN)**

## **WE CAN TALK ABOUT IT**

- Give the permission to the patient about sexuality
- Assess needs/questions

## **REASSURE**

- Normalization of the topic

## **EXPLICITMENT/CLARITY**

- Clear questions/clear answers

# TALKING TO YOUR KIDS ABOUT SEXUALITY WHEN THEY HAVE DM 1



# TALKING TO YOUR CHILDREN WITH DM 1 ABOUT SEXUALITY

- Many parents are nervous about approaching the subject of sexuality with their teenager, and having a teenager with a neuromuscular disorder may create additional questions.
- Remember that before being a teen with a neuromuscular disorder, your child is a teenager with the same sexual curiosity as any other teen.

# PUBERTY

- The hormonal development that comes with puberty happens to all adolescents.
- These changes inevitably lead to an exploration of one's own body and the accompanying sensations, including masturbation.
- This can sometimes be more complicated for young people with DM1 because of muscle weakness/myotonia.



# SELF-IMAGE

- Very important part of the teenage period
- Pressure from media and society
- You could look at some images together and encourage your teen to develop a critical view of advertising, or watch the videos on the Dove website
- Discussion is needed about this topic
  - Psychologist
  - Social worker

# ROMANTIC RELATIONSHIPS

- You may fear your teen will be rejected or hurt by the person to whom he or she is attracted.

**So ask yourself this question: “If my child didn’t have a physical/ intellectual disability, would I be so opposed to him or her having a romantic relationship?”**

**If the answer is No, you may need to work on yourself so as not to hinder your teen’s personal development.**

- As an adult, you have had more experience in interpersonal relationships, whether directly or indirectly. Each of these relationships has served to shape your ideas about love.

**What message I want to convey to my child about romantic love**

# SEXUAL RELATIONSHIPS

« It does not exist! »



**Dignity of taking risks**

# EXAMPLE

- If you are comfortable discussing this very intimate subject with your teen, you should know that there are technical aids, such as body harnesses, that can facilitate this self-exploration and you can contact your occupational therapist.
- Offer massage to your teenager so they experience the benefit of touching

# WHEN IS **THE** GOOD TIME TO TALK ABOUT IT

Certain attitudes are more conducive to sharing:

- Be available for your child
- Do not wait too long before addressing the subject
- Seize the opportunity to encourage discussion after seeing a movie or a commercial on a particular aspect of sexuality

**Educate yourself so you're not taken off-guard during a discussion.**

# THE MESSAGE IS THE KEY

- Before beginning a discussion on a topic involving sexuality, take stock of your own values on the subject.
- Ask yourself if you want your teen to share those values.
- Our opinions on a particular subject are often based on **our past experiences**, so we may need to qualify our words.
  - Often an issue with children who have a mild/severe intellectual disability

# KNOW YOUR LIMITS

- Be aware of your own limitations.
- If certain topics make you uncomfortable, it's OK to ask a health professional or other responsible adult to talk with your teen.
- At some schools and treatment centres, teens can speak to a nurse, a psychologist or other competent professional about sex-related issues.

# INTERNET DATING

- If your teen is interesting in online dating, you may want to set some limits, such as:
  - Do not share any personal information (telephone, address, school, etc.).
  - Do not send explicit photographs of or undress to someone online
  - If your online relationship is going well, and you want to arrange an in-person date, someone you trust should accompany your teen and the meeting should be in a public space (not in someones home).



# SEXUAL ASSAULT AND ABUSE

People with physical/intellectual disabilities are more vulnerable to sexual abuse

- Encourage your child to confide in you regarding any uncomfortable situation
- Approach the subject by asking your child if he/she knows the difference between appropriate and inappropriate touching.

You can explain that there are different forms of sexual abuse, including offensive words, inappropriate touching made to appear accidental, sexual solicitation.

**Empower your child to be assertive and speak out (say NO) against any form of inappropriate intimate contact**

# SEXUALITY ... NOT A SIMPLE PHYSICAL ACT

- **Physical act**
- Affection
- Love's life
- **Self-esteem**
- **Reproduction**
- **Couple's life**
- **Social relationships**
- **Sexual Identity**
- **Ethics**
- **Etc.**

# RÉFÉRENCES



- ◆ World Health Organisation (2006) Defining sexual health Report of a technical consultation on sexual health. Geneva. 30p.
- ◆ Dyer, K. and das Nair, R. (2013) Why don't healthcare professionals talk about sex? A systematic review of recent qualitative studies conducted in the United kingdom. *The journal of sexual medicine* 10(11):2658-2670.
- ◆ Taylor, B. and Davis, S. (2006) Using the extended PLISSIT model to address sexual healthcare needs. *Nurs Stand* 21(11):35-40.
- ◆ Gianotten, W.L.; Bender, J.L.; Post, M.W. and Höing, M. (2006) Training in sexology for medical and paramedical professionals: a model for the rehabilitation setting. *Sexual & Relationship Therapy* 21(3):303-317.
- ◆ Annon, J.S. (1976) The PLISSIT Model: A Proposed Conceptual Scheme for the Behavioral Treatment of Sexual Problems. *J Sex Educ Ther* 2(1):1-15.
- ◆ Vinci, P.; Gargiulo, P. and Navarro-Cremades, F. (2007) Sexuality in Charcot-Marie-Tooth disease. *Europa Medicophysica* 43(2):295-296.
- ◆ Marsden, R. and Botell, R. (2010) Discussing sexuality with patients in a motor neurone disease clinic. *Nursing Standard* 25(15-17):40-46.

# RESOURCES

- Come As You Are: This site addresses themes related to sexuality and includes a section for the physically disabled. There is also information on various sexual aids.  
<http://www.comeasyouare.com/>
- Miriam Kaufman, Cory Silverberg and Fran Odette. *The Ultimate Guide to Sex and Disability: For All of Us Who Live with Disabilities, Chronic Pain, and Illness*. Cleis Press, San Francisco, 2007.