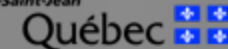




**SUPPORTING
PATIENTS
DM1 AND
SEXUALITY FOR
CLINICIANS**



Centre intégré
universitaire de santé
et de services sociaux
du Saguenay-
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SEXUALITY OR WHAT ARE WE REALLY TALKING ABOUT

- "Sexuality is expressed throughout life through **identities and eroticism, pleasure, reproduction** expressed in **beliefs, attitudes, practices, roles** sexuality can be all of them are [...] [...]



Influence of DM1 on expressing sexuality
Medical/Rehabilitation perspectives

nce d
desires,
ours,
s. While
mensions, not
or expressed.

(Organisation mondiale de la santé 2006)

SEXUALITY ... NOT A SIMPLE PHYSICAL ACT

- **Physical act**
- **Affection**
- **Love life**
- **Self-esteem**
- **Reproduction**
- **Couple's life**
- **Family 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 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**

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

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

« It does not exist! »



« Of course, but not my role »



CHALLENGES

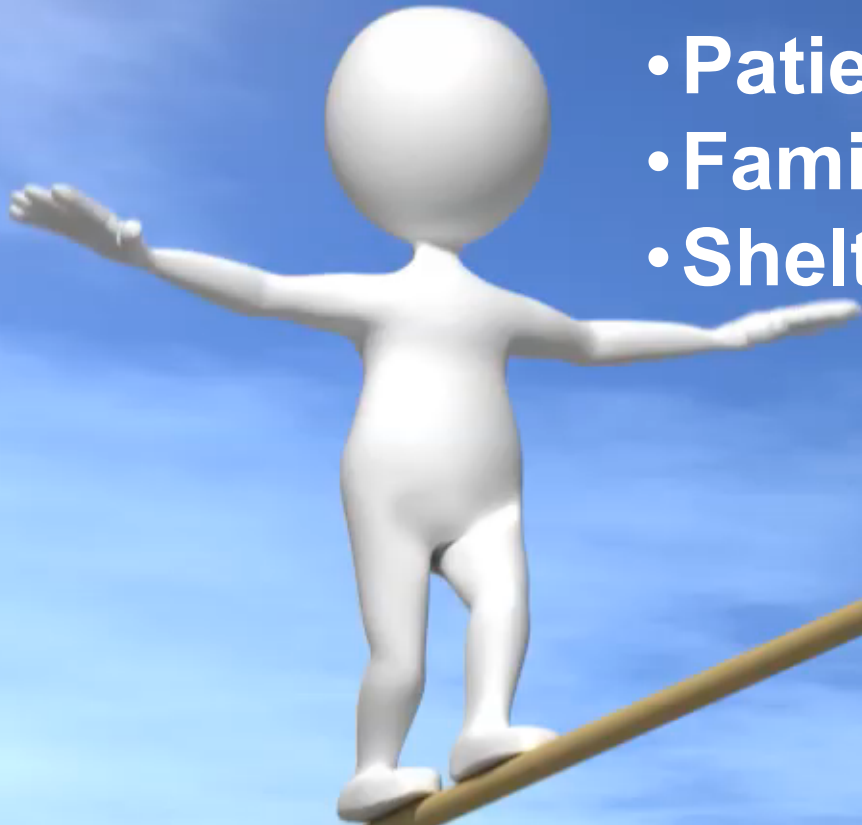
- **Subject often not discussed**
- **What is really sexuality/
preconception**
- **Patients expect clinicians to talk
to them about it**
- **Healthcare professionals do not
feel comfortable addressing this
with their patients**
 - **Very few training**
 - **Specific resources**

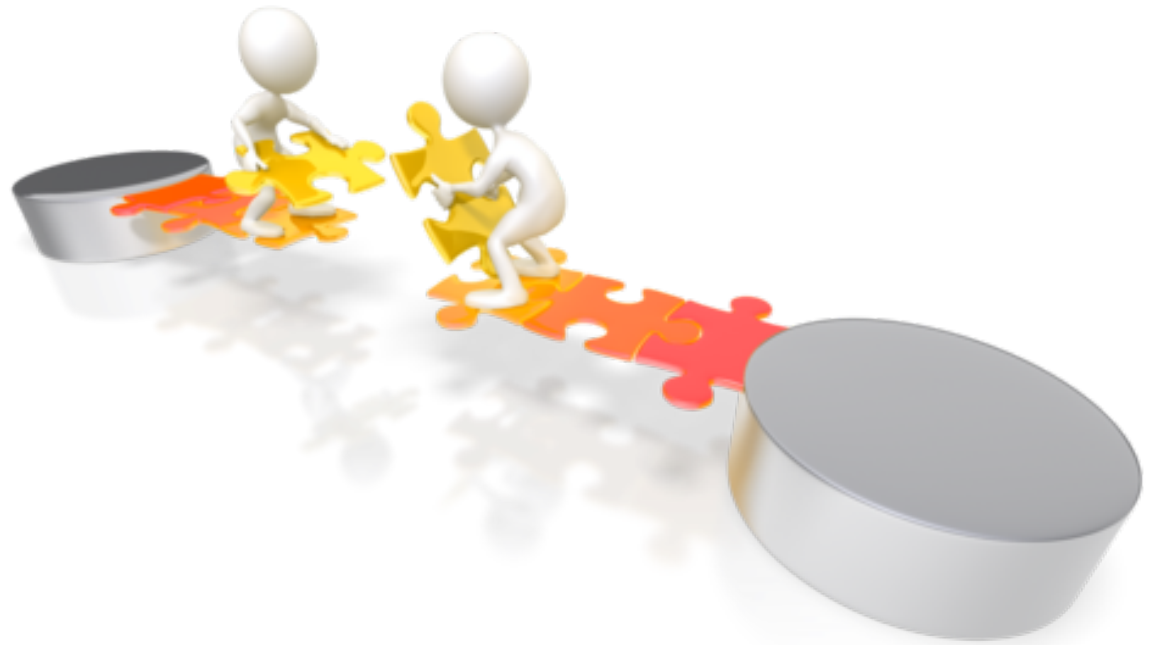


(Dyer 2013, Gianotten 2006, Taylor 2006)

TABOU...

- Healthcare professionals
- Patients
- Family
- Sheltered housing...





BRIDGING THE GAP

A DUAL RESPONSIBILITY

How to talk about sexuality

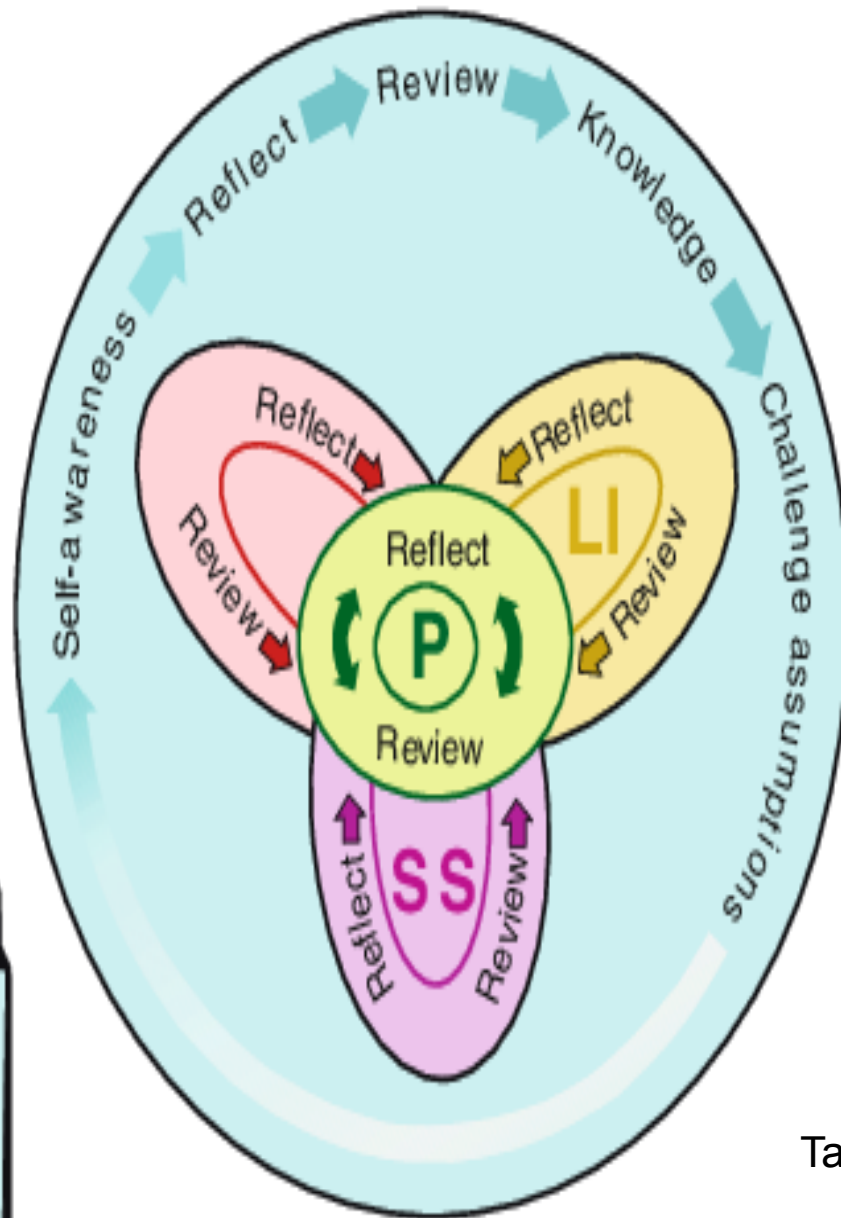
EX-PLISSIT

(Annon 1976, Taylor 2006)



The Extended PLISSIT Model

KEY	
P	Permissiongiving
LI	LimitedInformation
SS	SpecificSuggestions
IT	IntensiveTherapy



Taylor 2006

EX-PLISSIT

Stage 1 PERMISSION-GIVING

WE CAN

- Give
- Ass
- Po

• **P**

• **I**

• **S**

- Open direct

People with DM1 often
mention that
[symptoms] interfere
with their sexuality

~~Do you~~

How is your experience
with this ?



OPPORTUNITIES FOR PERMISSION-GIVING

- **New patient registration**
- **Contraception**
- **Waiting room information and poster**
- **Discussion around bringing the bed downstairs**
- **Annual evaluation : include it in the process**

PERMISSION ↔ INFORMATION

- Often linked
- Information linked to expressed needs

IMPACTS

- Impact of illness on sexuality
- Effect of treatments on sexual function

CLARIFICATION

- Clarifying misinformation, dispelling myths
- Factual information in a limited manner (leaflet, website, etc.)

Niveau 1
AUTORISATION

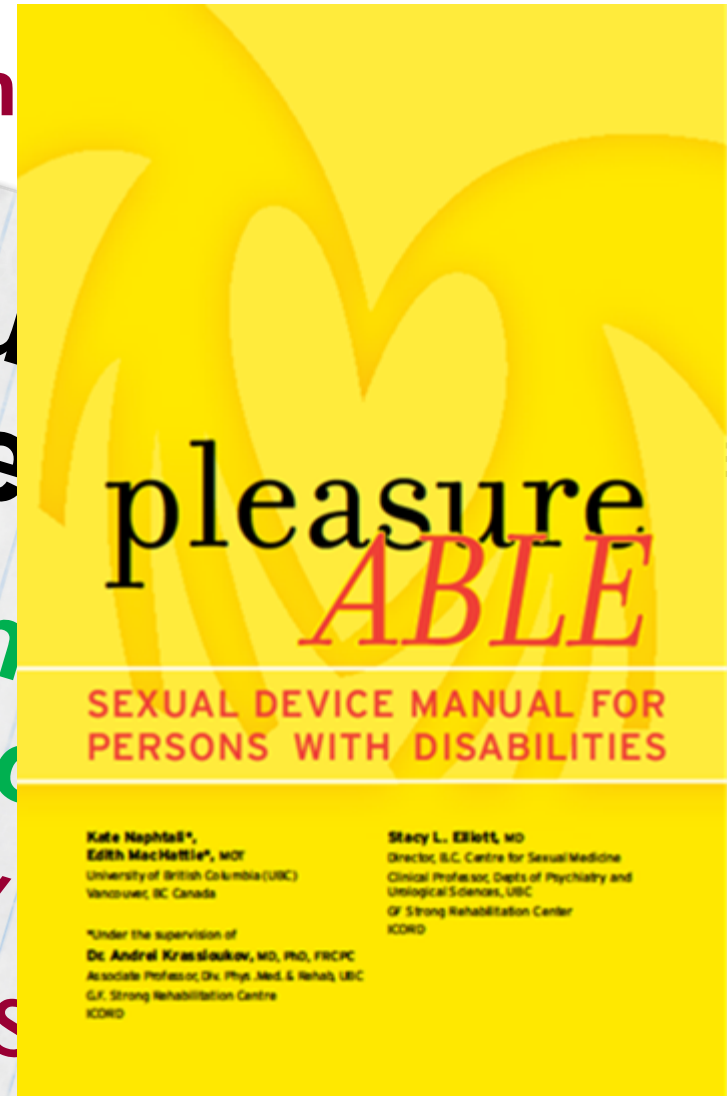
Problems

- All aspects
- Specific
- Ex
- F

Muscle
weakness

To experiment
sexual position

... for example, by
yourself on the s



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ICORD

EX-PLISSIT

Stage 4 INTENSIVE THERAPY

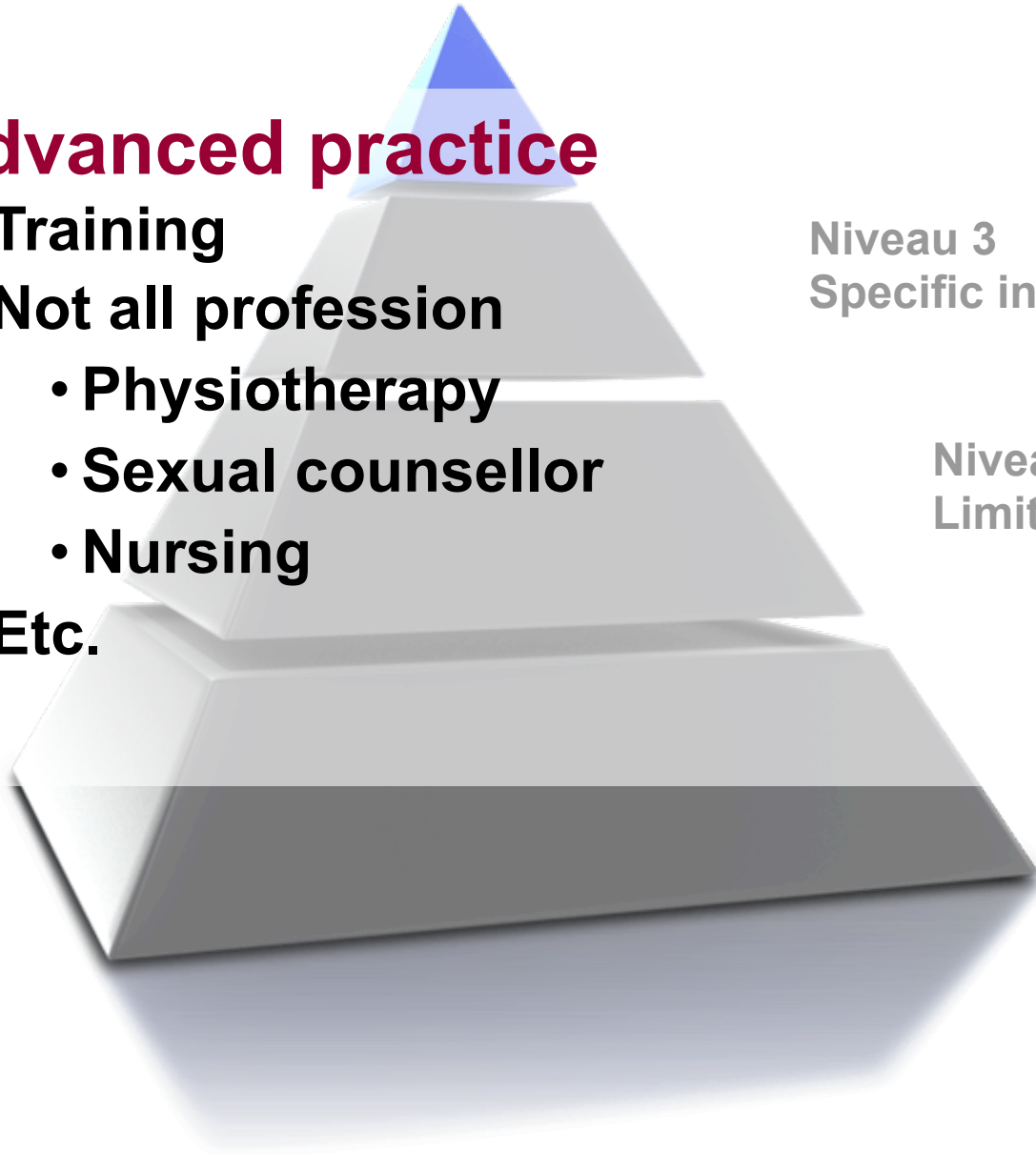
Advanced practice

- Training
- Not all profession
 - Physiotherapy
 - Sexual counsellor
 - Nursing
- Etc.

Niveau 3
Specific instructions

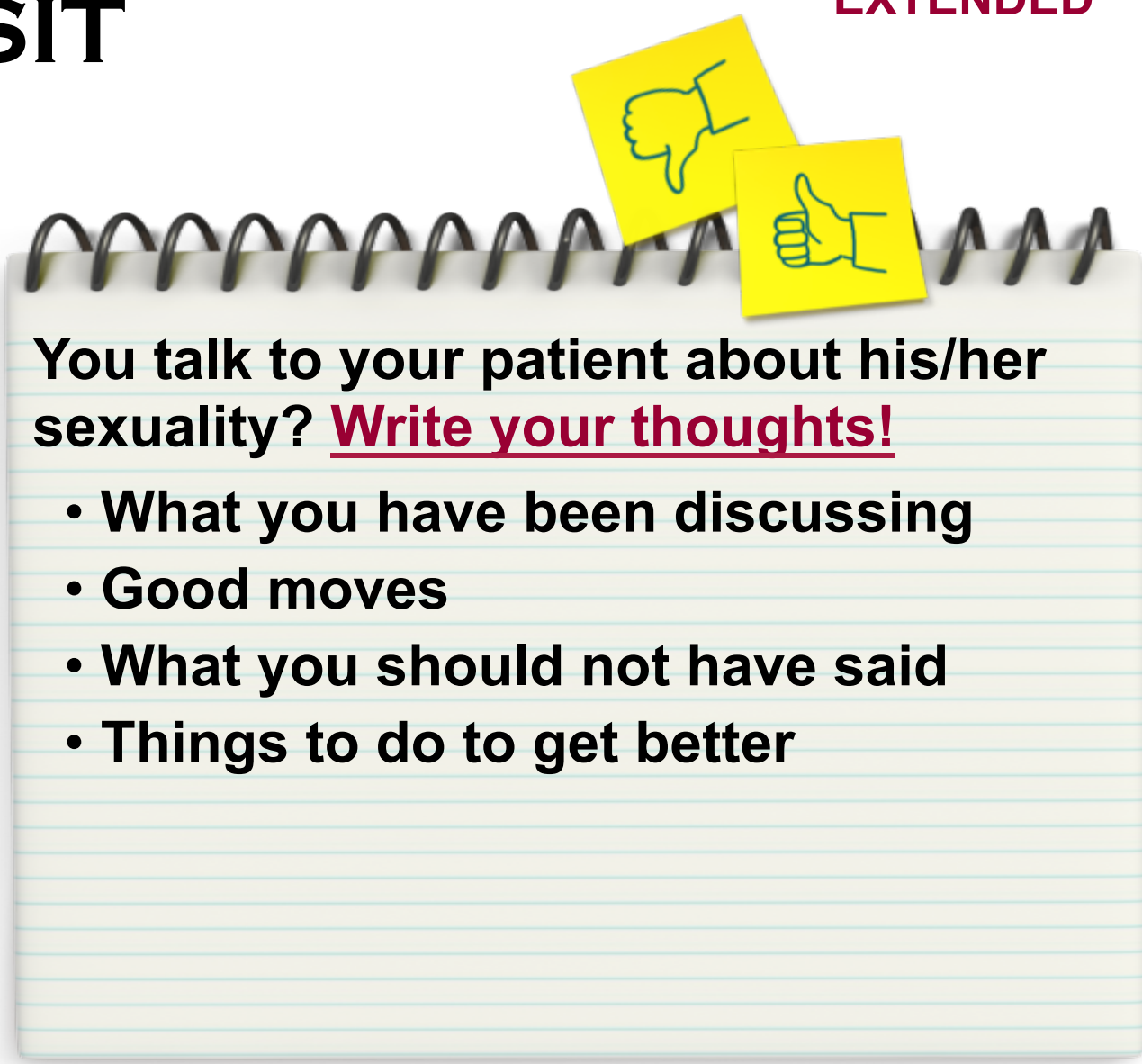
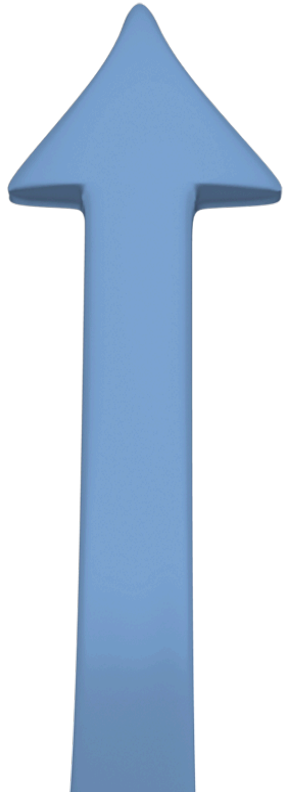
Niveau 2
Limited information

Niveau 1
Permission-giving



EX-PLISSIT

EXTENDED



You talk to your patient about his/her sexuality? Write your thoughts!

- What you have been discussing
- Good moves
- What you should not have said
- Things to do to get better

Continuum

Continuous review process



**TO TALK ABOUT IS THE BEGINNING OF A
GREAT SUCCESS**

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